

September 30, 2009

WASHINGTON, DC - U.S. Rep. Michael Arcuri (NY-24) led a resolution on the floor of the House of Representatives to bring attention to the deadly neurological disease Tay-Sachs by recognizing September 2009 as "National Tay-Sachs Awareness Month."

"I am pleased have the opportunity to again bring the nation's attention to a deadly disease that has the potential to impact nearly 1.5 million Americans," **Arcuri said**, "We must remain vigilant in finding a cure for this horrific disease by ensuring that researchers have the resources they need to address thousands of rare diseases that often don't get the attention they deserve. Raising awareness is the first step towards finding a cure for Tay-Sachs once and for all."

Tay-Sachs disease is a rare, genetic disorder that causes destruction of nerve cells in the brain and spinal cord due to poor functioning of an enzyme called hexosaminidase A. Roughly 1.5 million Americans are carriers of Tay-Sachs disease, which often affects families with no prior history. Unaffected carriers possess the recessive gene that can trigger the disease in future generations; if both parents of a child are carriers of Tay-Sachs, there is a 1 in 4 chance the child will develop the disease. Approximately 1 in 30 American Jews, 1 in 30 Louisianan Cajuns, 1 in 30 French Canadians, and 1 in 50 Irish Americans are carriers of the disease.

Infants with Tay-Sachs disease appear to develop normally for the first few months of life, until a relentless deterioration of mental and physical abilities begins to occur. As muscles begin to atrophy and paralysis sets in, the child becomes blind, deaf, and unable to swallow. A much rarer form of the disorder, which occurs in patients in their twenties and early thirties, is characterized by an unsteady gait and progressive neurological deterioration. There is no proven treatment or cure for Tay-Sachs disease, and it is always fatal in children - usually by the age of four.

The resolution introduced by Arcuri also brings attention to the fact that a simple and inexpensive blood test can determine if an individual is a carrier of Tay-Sachs disease, and states that all people in the United States, especially those people who are members of high-risk populations, should be screened. High risk populations include Jewish-Americans, Louisiana Cajuns, French Canadians and Irish Americans.

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